



**STATE OF CONNECTICUT**  
**OFFICE OF PROTECTION AND ADVOCACY FOR**  
**PERSONS WITH DISABILITIES**  
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**Testimony of the Office of Protection and Advocacy for Persons with Disabilities**  
**Before The Public Health Committee regarding**

R. B. No. 6521, AN ACT CONCERNING MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT

Submitted by: James D. McGaughey  
Executive Director  
March 15, 2013

Thank you for this opportunity to comment on Raised Bill No. 6521, An Act Concerning Medical Orders for Life-Sustaining Treatment (MOLST).

This bill would establish a pilot program, in one region of the State, implementing a procedure for memorializing and acting on a transportable medical order that details the types and levels of emergency intervention and life supporting treatment that a person who is near the end of their life wants. Participation would be voluntary on the part of patients and providers.

Our Office's interest in this matter stems from our experiences representing individuals with significant disabilities who have had "Do Not Resuscitate" (DNR) orders inappropriately entered on their medical charts, or who have otherwise been denied beneficial medical treatment at the request or with the consent of family members or guardians. By "inappropriate", I mean circumstances where the individual did not have a terminal diagnosis or a condition where resuscitative efforts or life-sustaining treatments such as dialysis, diagnostic procedures, surgical interventions, or the provision of supplemental nutrition or hydration were contraindicated or would be considered futile. In each case, an appointed surrogate decision maker had requested or consented to the orders to withhold treatment, usually based on their own subjective perceptions about the individual's "quality of life", not based on any discussion or understanding they had previously reached with the individual.

I understand that the principal benefit of establishing a MOLST program lies with the mechanism it establishes to ensure that the wishes of a person who is approaching the end of his or her life can be made explicit and recorded on a clearly recognizable official form which is then signed by the person's physician as a "medical order". That form can transfer along with the individual between various settings, and will be respected by health care providers in those different settings and by Emergency Medical Services personnel if they are called to the person's home or beside.

While the clarity and simplicity of the forms used will no doubt prove helpful in many cases, the fact that a MOLST form is to be accepted without question suggests that considerable care must be taken to ensure that the information it captures is, indeed, what the person wants. I note that the bill requires that an individual consent, in writing, to participate in the MOLST pilot. I would suggest that a requirement also be added to the effect that the person must also sign the completed MOLST form

along with his or her treating physician, and that the form also be required to prominently state that the individual may, at any time, change his or her mind and revoke any or all of the decisions reflected on the form.

Mindful of our experience intervening in the cases referred to above, where appointed surrogates have based their decisions about consent for various medical tests, procedures and interventions on their own subjective perceptions of an individual's "quality of life", I would also suggest that a requirement be added to the effect that before a court-appointed guardian or conservator of the person makes decisions about any of the specific areas of care reflected on the MOLST form, he or she must seek specific approval of those decisions from the probate court that appointed him or her, and that the probate court must send notice of the proposed decisions that will be reflected on the MOLST form to any interested parties that had been notified of the original guardianship or conservatorship proceeding, along with an offer to hold a hearing if any party so requests. This requirement would not need to apply to a health care representative selected or designated by the person him or herself, as provided for in Section 19a-576 of the General Statutes.

Thank you for your interest in this matter. If there are any questions, or if our Office can be of assistance to the Committee, please do not hesitate to contact me.